

lupus **FACT SHEET**

LEARNING TO LIVE WELL WITH LUPUS : Preventative Coping Strategies for Physical Health

Lupus is a lifelong, incurable disease that may require lifestyle changes and adjustments. The challenge facing many of those living with lupus is that the disease can affect many aspects of daily life, such as physical functioning, the ability to work outside the home and earn an income, and socializing with friends and family. People living with lupus often need to adapt to complicated medical regimens to control symptoms and prevent disease flares. Making gradual and achievable lifestyle adjustments can help improve quality of life and provide a sense of well being.

Each person with lupus experiences different signs and symptoms so a personalized learning plan is needed. To help yourself live well with lupus, it's important to learn physical measures and develop preventative coping strategies. Some of these approaches may be useful in your situation and others may not be practical. Start with something you think might be enjoyable and something you will be able to accomplish. This will give you confidence to try other methods and will make it easier to add to your own personal plan.

Learning physical measures.

Avoid sun exposure. Use a sunscreen lotion that has a sun protection factor (SPF) of 30 or over. The SPF prevents ultraviolet A and B rays from causing rashes and/or activating lupus disease activity. Plan outdoor activities to avoid the most intense times of sun exposure between the hours of 10 a.m. and 3 p.m. Wear loose, protective clothing with long sleeves and pant legs. Protect your face with a large-brimmed hat. Remember that the intensity of

ultraviolet rays increases at higher altitudes, so if you are hiking or skiing in the mountains, be more cautious.

Eat well. Optimize healthy food choices. This sounds so simple, but it is difficult to change a pattern of eating foods that, over the years, could be aggravating or causing additional health problems that may or may not be related to lupus. Start by considering and following these few simple “wellness tips” :

- balance calories consumed with calories burned; the amount of physical activity required to burn off high-calorie, fast food meals is much higher than the activities required for lower-calorie, generally healthier foods
- select natural foods as they are healthier and more nutritious; fast food or pre-packaged foods tend to have more calories and fat
- choose foods that contain plenty of complex carbohydrates and fibre. This includes a variety of grains, nuts, vegetables and fruits. Ensuring your diet that includes more than 5 servings of different fruits and vegetables per day will help optimize health-enhancing nutrients.
- keep yourself well hydrated with water – normally at least two litres of water every day. However, some people, for medical reasons such as kidney or heart failure, should restrict this intake; discuss with your doctor in these cases.
- be aware of the fat you consume, lower your intake of animal fats (saturated fats), which tend to contribute to heart disease and cancer. Fish oils may be beneficial for those with lupus.

Some studies suggest that a diet including fresh cold water fish, such as salmon, or fish oil supplements (containing omega-3 fatty acids), might have a modest anti-inflammatory effect. Watch out for trans-hydrogenated fats (commonly found in processed foods) as these have been linked to heart disease.

- in the place of saturated and trans-hydrogenated fats, substitute unsaturated fats, as found in fish, nuts, seeds, and some vegetable oils, especially olive oil.
- although there is no strong evidence that particular vitamins or minerals are helpful to maintain health in lupus, it is known that in general vitamin C and vitamin E may have anti-inflammatory effects. B complex vitamins are popular as “anti-stress” vitamins. A multi-vitamin containing at least 400IU per day of vitamin D is a good choice for lupus patients, since this may help maximize bone strength. Recommendations for optimizing bone strength include 400-800IU of vitamin D and 1000-1500 mg of elemental calcium per day as a minimum. If you are taking corticosteroids, if you are menopausal, or if you have osteoporosis (bone thinning) or a history of fractures, you need specific instruction from your rheumatologist about calcium and vitamin D. Also note that if you have problems with kidney function, daily recommended amounts of calcium and vitamin D may be quite different, so you need to speak to your specialists about this.

- avoid extreme diets, and be wary of those that promise “miracle results.”
- many people believe that a healthy breakfast every day is a helpful, energetic start to wellness
- limit your intake of caffeinated coffee; to avoid problems with sleep disturbances don’t consume caffeinated beverages late in the day. Cola beverages have been associated with osteoporosis, so try to stay clear of these.

Get active. The physical functioning of your body has an enormous influence on your mind and your ability to deal with the day-to-day challenges of living with lupus. Pain, fatigue and a range of symptoms and problems can stand in the way of engaging in physical activity. But it’s important to find ways to do so. With

Smoking can aggravate many problems in lupus, such as Raynaud’s phenomenon

prolonged inactivity, we become less energetic, lose muscle tone and balance, and place ourselves at higher risk for developing further health problems. The key to starting any exercise or activity program, particularly if you have been inactive for a long period of time, is to start slow, set short-term goals you are sure to reach, and begin by doing something you enjoy. Starting an activity program with a friend may give you the added incentive to stick to it. Gradually work your way up to 30-45 minutes of exercise or more at least 5 days each week. Try walking part way to work, take the stairs when you can, walk on your lunch hour with a friend. Swimming is a good low impact aerobic activity. Try to weave your activity plan into your daily routine so it becomes a natural part of your day rather than an “extra” that can

quickly be dropped if you become busy. The benefits of physical exercise are numerous and can include:

- stronger bones
- increased strength
- improved sleep
- decreased blood pressure and better cholesterol levels
- weight loss or maintenance
- improved flexibility
- enhanced energy
- improved stress management
- better glucose metabolism, especially for type-II diabetics

Consider consulting an occupational therapist (OT) or physiotherapist (PT) to help you learn to overcome barriers or problems as you learn to include activity in your day-to-day routine. Talk to your doctor or other health care professionals about where you could seek the assistance of OTs or PTs.

They work in the public health care system and in private practice settings.

Stop smoking. This is the single most important action you can take to improve your health immediately. Smoking can aggravate many problems in lupus, such as Raynaud's phenomenon, and is well known to increase the risk of cardiovascular disease. Due to the inflammatory nature of lupus, people who have it are already at increased risk for cardiovascular disease. Studies have shown that smoking decreases the effectiveness of antimalarial medications, a very important treatment for many people with lupus. Talk to your doctor about methods to assist with smoking cessation. A nurse, psychologist or social worker with skills in this area can be of assistance. There are also many

community resources as well as services and programs in the public health system.

Manage your pain and fatigue. Some of the physical causes of symptoms in lupus can be related to an increase in inflammation and disease activity in lupus. Pain management in lupus is an important physical measure because, if left untreated, pain can lead to increased fatigue and stress and can contribute to depression.

Don't ignore the psychological and spiritual elements of your whole-person wellness. Improving communication in personal relationships,

optimizing your community networks, involvement with organizations and causes that you believe in, and spiritual practices such as prayer and meditation may all be helpful to you as you learn to live well with lupus.

Try to weave your activity plan into your daily routine so it becomes a natural part of your day

Systemic Lupus Erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from patient to patient and treatment is highly individualized. Patients are urged to contact their physician or health professional with any questions or concerns they might have. For more resources and information about lupus, visit the Lupus Canada website at www.lupuscanada.org

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Working together to conquer lupus